



Special Olympics

Health

MADE
POSSIBLE BY **Golisano** FOUNDATION

LEARNING TO USE THE HEALTH SYSTEM

Getting Started + Editing Guidelines

Welcome!

Read Me First

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Getting Started

Welcome to “Learning to Use the Health System,” a series of learning sessions for people with intellectual and developmental disabilities (IDD) and their caregivers. Thank you for sharing this important content with your community!



Sessions

There are five **(5) sessions** in this series:

- Session 1: Fundamentals
- Session 2: Know Your Rights
- Session 3: Self-Advocacy / Supporting Self-Advocacy
- Session 4: When + Where to Get Care
- Session 5: Going to the Doctor



Versions

There are two **(2) versions** of each session:

- **The green version** is for use by people with intellectual and developmental disabilities (IDD)
- **The orange version** is for use by **caregivers** of people with intellectual and developmental disabilities (IDD)



For use by people with intellectual and developmental disabilities (IDD)



For use by caregivers of people with intellectual and developmental disabilities (IDD)

These sessions have been designed with the **different needs** of each group in mind:

- We recommend that people with IDD participate in the sessions **without** their primary caregiver(s) present.
- If possible, we recommend that caregivers participate **without** the person they help care for present. If that arrangement won't work for your local context, you can do it a different way.



Materials

The materials for each version of each session include **(3) different files**:

- A **participant workbook** for use during the sessions (choose between PDF or .docx editable version)
- A **PowerPoint slide deck** (.pptx)
- A **facilitator guide** (choose between PDF or .docx editable version)
 - Facilitators should also keep a copy of the participant workbook on hand for reference while leading sessions. The page numbers of the workbook don't always match the corresponding slide numbers.



Session Delivery

These learning sessions can be delivered in person, online, or in a hybrid setting. When possible, **we recommend leading sessions in person** for the best results. However, you can decide what makes sense based on your local context.

The sessions can be facilitated by a Special Olympics Program staff member, or you can **engage a community partner** as a facilitator. Whoever facilitates the sessions, they should have experience in health systems navigation and/or expertise working with people with IDD. Appropriate outside organizations to engage could include your [local Arc chapter](#), your local [Protection & Advocacy organization](#), a [Statewide Independent Living Council or Center for Independent Living \(CIL\)](#), and more.

It's best to schedule each learning session for **75-90 minutes** so you have ample time to cover all the content, as well as to include any activities, discussion, questions, and breaks. You can always add more breaks or let people go early if you finish before the time is up.



Advertising the Sessions

On the next page is a simple **email template** you can edit to advertise these sessions to your community.

Dear Community,

Join us for a **5-part educational series** called “Learning to Use the Health System.”

There are two versions of the series:

- The **caregiver version** is designed to help parents and caregivers support their child / sibling / loved one with IDD as they learn to navigate the health system.
- The **IDD version** is designed to help people with IDD understand the health system and learn to advocate for their own needs.

Below are the dates and times for each session. Sessions will be held [in-person / virtually / hybrid. Add relevant info]. Participants should plan to attend at least 4 of the 5 sessions.

- **Session 1: Fundamentals.** This session covers main ideas about health and healthcare and explains why it’s important to learn about them.
 - Caregiver Version: [Date, Time]
 - IDD Version: [Date, Time]
- **Session 2: Know Your Rights.** This session is about the rights of people with disabilities and how those rights protect them from discrimination. It also talks about accommodations people with disabilities can ask for to get better care.
 - Caregiver Version: [Date, Time]
 - IDD Version: [Date, Time]
- **Session 3: Self-Advocacy / Supporting Self-Advocacy.** This session explains how to express needs and feelings / how to support someone to express their needs and feelings, so people with IDD get better care.
 - Caregiver Version: [Date, Time]
 - IDD Version: [Date, Time]
- **Session 4: When + Where to Seek Care.** This session explains how to stay healthy, how to spot signs of sickness, and when and where to go if you need medical care.
 - Caregiver Version: [Date, Time]
 - IDD Version: [Date, Time]
- **Session 5: Going to the Doctor.** This session explains what to do before, during, and after you visit a healthcare provider.
 - Caregiver Version: [Date, Time]
 - IDD Version: [Date, Time]

Parents/caregivers and athletes who participate in at least 4 of the 5 sessions will receive [incentive].

Space is limited to ensure meaningful participation. Register today to secure your spot!

Caregiver registration [link]

IDD registration [link]

Let me know if you have any questions about this valuable opportunity.

Warmly,

[Your Name]



Questions?



For questions or support, please contact inclusivehealth@specialolympics.org. We're here to help.

Thank you, and good luck!

Your SOI Inclusive Health Team

Editing Guidelines

At times, you may wish to **change something** in these materials to make the learning sessions as relevant as possible to your community. For example:

-  You might wish to **add** local laws or community resources into the slide deck or participant workbook.
-  You might wish to **change** an image and replace it with something more fitting to your local social and cultural context.

Adding Content

If you decide to **directly edit** the original drafts, be mindful of how your changes affect the overall formatting of the material. Most of the images and other visual elements of the documents are inserted inline with the text, so changes to the text may affect images in some cases. Take your time with editing, and save your progress as you go. If you want to make sure the formatting is consistent for all users, you can save your edited participant workbooks as PDFs. If you want users to be able to make their own edits, you can leave the documents as .docx files.

If you don't want to edit the originals, you can also **verbally share** location-specific information and resources with participants during the sessions. Or, you can supplement the materials with **additional handouts**. It's up to you!

Changing Images

Before each session, you may want to take some time to **review all the images** in the slide deck and participant workbook to make sure the images are **appropriate for your local social and cultural context**. Images used in the slide deck are usually **repeated** in the workbook, so if you change one, be sure to change the other.

Where Do I Start?

On the next page is a list of numbered slides and pages where you may wish to add location-specific information. For images, different locations may have different needs. As a reminder, **review the images** used in each session in case you need to make changes. Whatever images you use, they should tell a story and improve understanding.

Session 1

Caregiver Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- Pages 9-10: Medicaid, Developmental Disability services, and SSI are mentioned. You could add state-specific eligibility guidelines here, or you could share additional materials like the “Understanding Medicaid” information sheet, [published by SOI](#).
- Page 11: If your local Medicaid member card is significantly different from the one shown in the graphic, you could add it here in place of the example. Or, you can mention differences verbally.
- Page 14: If there is a particular local program that helps with the transition from pediatrics to adult care, you could include it here.
- Page 16: Review the images on this page to be sure they’re appropriate for your local social and cultural context.
- Pages 24-27: You may wish to edit the Glossary of Acronyms to include any common acronyms that you use locally. Make sure to leave some blank spaces at the end for participants to add their own.
- Page 29: This page has a blank pod mapping exercise that participants can fill out. Some of them may choose to fill it out in their workbook, and others may prefer to fill it out on a loose piece of paper so they can hang it up on the wall somewhere at home. Facilitators may want to **print several copies of this page before the session** to give participants the option to take a loose copy.

Slide Deck

- Slide 10-11: Medicaid, Developmental Disability services, and SSI are mentioned. You could add state-specific eligibility guidelines here, or you could share additional materials like the “Understanding Medicaid” information sheet, [published by SOI](#).
- Slide 12: If your local Medicaid member card is significantly different from the one shown in the graphic, you could add it here in place of the example. Or, you can mention differences verbally.
- Slide 15: If there is a particular local program that helps with the transition from pediatrics to adult care, you could mention it here.
- Slide 17: Review the images on this page to be sure they’re appropriate for your local social and cultural context.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
 - If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
 - The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.
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IDD Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- Page 8: If your local Medicaid member card has a significantly different design from the one shown in the graphic, you could add it here in place of the example.
- Page 9: You can find the information for your local [Center for Independent Living \(CIL\)](#) or [Statewide Independent Living Council \(SILC\)](#) in advance of the session and share it with participants if desired.
- Page 10: Review the images on this page to be sure they're appropriate for your local social and cultural context.
- Page 15: Review the images on this page to be sure they're appropriate for your local social and cultural context.

Slide Deck

- Slide 9: If your local Medicaid member card has a significantly different design from the one shown in the graphic, you could add it here in place of the example.
- Slide 11: Review the images on this page to be sure they're appropriate for your local social and cultural context.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.

- If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
- The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.

Session 2

Caregiver Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- Page 14: If you want to look up your local [Protection & Advocacy Agency](#) in advance, you could share that information with participants when it's mentioned in the session.
- Pages 22-25: The activity for caregivers in Session 2 is to review a sample health passport and make plans for filling one out. The facilitator should review the templates linked on page 22 before the session and choose their favorite to use for the activity (the sample pages shown on page 23 are from the [My Health Matters](#) folder made by the Australian Council for Intellectual Disability). Later, caregivers can go back and review the other options, and they can choose to fill out a different template if they like it better. **No changes to the participant workbook are necessary**, but facilitators should prepare their materials for this section accordingly.

Slide Deck

- Slide 12: If you want to look up your local [Protection & Advocacy Agency](#) in advance, you could share that information with participants when it's mentioned in the session.
- Slides 21-24: The activity for caregivers in Session 2 is to review a sample health passport and make plans for filling one out. The facilitator should review the templates linked on page 22 of the participant workbook before the session and choose their favorite to use for the activity (the sample pages shown on slide 22 are from the [My Health Matters](#) folder made by the Australian Council for Intellectual Disability). Later, caregivers can go back and review the other options, and they can choose to fill out a different template if they like it

better. **No changes to the slide deck are necessary**, but facilitators should prepare their materials for this section accordingly.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
 - If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
 - The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.
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IDD Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- Pages 16-21: The activity for people with IDD in Session 2 has to do with reviewing accommodation stories. The facilitator can decide what type of activity would work best for the people in their group. For example:
 - You might decide to pair people up and have them read one of the stories together and then talk about what they read to make sure they understand.
 - Or, you can read one or two stories as a big group and discuss them together.
 - Some groups might even feel comfortable acting out the stories by pretending to be the patient and the provider, and then practicing asking for accommodations. It's up to you!
 - Some specific ideas are included in the facilitator guide for Slide 16. **No changes to the participant workbook are necessary**, but facilitators should review the stories before the session and decide what type of activity would be the best fit for their situation.
- Page 23: If you want to look up your local [Protection & Advocacy Agency](#) in advance, you could share that information with participants when it's mentioned in the session.

Slide Deck

- Slides 16-17: The activity for people with IDD in Session 2 has to do with reviewing accommodation stories. The facilitator can decide what type of activity would work best for the people in their group. For example:
 - You might decide to pair people up and have them read one of the stories together and then talk about what they read to make sure they understand.
 - Or, you can read one or two stories as a big group and discuss them together.
 - Some groups might even feel comfortable acting out the stories by pretending to be the patient and the provider, and then practicing asking for accommodations. It's up to you!
 - Some specific ideas are included in the facilitator guide for Slide 16. **No changes to the slide deck are necessary**, but facilitators should review the stories before the session and decide what type of activity would be the best fit for their situation.
- Slide 19: If you want to look up your local [Protection & Advocacy Agency](#) in advance, you could share that information with participants when it's mentioned in the session.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
- If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
- The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.

Session 3

Caregiver Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.

- Page 18: This page has a blank support plan worksheet that participants can fill out in partnership with the person they care for. Facilitators may want to **print several copies of this page before the session** to hand out to participants so they don't have to tear the page out of their workbooks. Facilitators may also choose to share the PDF version of the participant workbook with participants, so they can print the appropriate page at home.

Slide Deck

- The information in Session 3 should be consistent regardless of your location. No changes or additions to the slide deck are recommended.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
 - If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
 - The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.
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IDD Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- Page 25: This page has a blank support plan worksheet that participants can fill out in partnership with their caregiver(s). Facilitators may want to **print several copies of this page before the session** to hand out to participants so they don't have to tear the page out of their workbooks. Facilitators may also choose to share the PDF version of the participant workbook with participants, so they can print the appropriate page at home.

Slide Deck

- The information in Session 3 should be consistent regardless of your location. No changes or additions to the slide deck are recommended.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
- If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
- The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.

Session 4

Caregiver Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- The information in Session 4 should be consistent regardless of your location. No changes or additions to the workbook are recommended.

Slide Deck

- The information in Session 4 should be consistent regardless of your location. No changes or additions to the slide deck are recommended.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
- If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
- The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.

IDD Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- The information in Session 4 should be consistent regardless of your location. No changes or additions to the workbook are recommended.

Slide Deck

- The information in Session 4 should be consistent regardless of your location. No changes or additions to the slide deck are recommended.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
- If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
- The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.

Session 5

Caregiver Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- The information in Session 5 should be consistent regardless of your location. No changes or additions to the workbook are recommended.

Slide Deck

- The information in Session 5 should be consistent regardless of your location. No changes or additions to the slide deck are recommended.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.

- If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
 - The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.
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IDD Version

Participant Workbook

- Table of Contents: if you change any of the section headings, be sure to refresh or edit the Table of Contents accordingly.
- The information in Session 5 should be consistent regardless of your location. No changes or additions to the workbook are recommended.

Slide Deck

- The information in Session 5 should be consistent regardless of your location. No changes or additions to the slide deck are recommended.

Facilitator Guide

- Edits to the facilitator guide can be made directly into the editable .docx file for the appropriate guide.
- If you make changes to your slide deck, update the images in your facilitator guide so the thumbnail for each slide matches what participants see. This is particularly important if you add slides: you'll want to add corresponding pages to your facilitator guide, too.
- The sample scripts are just suggestions for what the facilitator can say for each slide. It's okay if facilitators have a different style or approach to teaching the content, so long as the main ideas come across.